TOWARDS
INTEGRATED CARE
WORKFLOWS   **DECEMBER 2016**

COCIR

SUSTAINABLE COMPETENCE IN ADVANCING HEALTHCARE

European Coordination Committee of the Radiological, Electromedical and Healthcare IT Industry

COCIR

EXECUTIVE SUMMARY

Currently, care workflows are routinely defined by best practices set by multidisciplinary teams within a given care organisation; they cover a specific disease and a standard patient profile. Such static care pathways present a barrier to delivering truly 'person centred' care, by treating patients with the same disease and similar characteristics in the same way, rather than adapting care to the specific needs of the individual.

It is feasible to develop shared and dynamic care workflows for integrated medical teams that respond to clinical and operational changes and enable data sharing between all stakeholders in the care pathway. However, given the amount of information and resources involved, such workflows cannot be realised without support from information and communication technologies (ICT).

Cultural, legal and financial challenges hinder data sharing and greater coordination across the care pathway. In addition, clinicians' attitudes and lack of faith in ICT solutions also slows development and uptake of Integrated Care pathways. Beyond these barriers, COCIR has identified six specific challenges that need to be overcome to develop shared and dynamic care workflows:

1. MULTI SOURCED DATA THAT NEEDS TO BE JOINTLY ANALYSED
2. LIMITS OF CURRENT REASONING ENGINES
3. LACK OF HEALTH DATA GOVERNANCE FRAMEWORKS
4. LIMITS OF REGIONAL AND NATIONAL eHEALTH INFRASTRUCTURES
5. SHARING SEMANTICALLY RICH HEALTH RECORDS
6. USABILITY OF ICT SYSTEMS

COCIR RECOMMENDATIONS

To accelerate development and uptake of shared and dynamic care workflows capable of supporting the delivery of Integrated Care, COCIR believes that Health ICT vendors, Member States and European Data Protection Authorities need to take the following actions:

ACTIONS BY HEALTH ICT VENDORS:

1. **Deliver** new technologies that can combine different and heterogeneous data sources to demonstrate the feasibility of using Big Data in real world settings.

2. **Develop** new approaches to cope with the combinatorial explosion of data and medical knowledge, new generation of reasoning and analytical engines.

3. **Design** IT systems for information management and knowledge representation that take into account the relationship between technologies and their social and human context and **develop** ways of measuring the effectiveness and "kindness" of new user interface approaches.

ACTIONS BY MEMBER STATES AND THE EUROPEAN DATA PROTECTION AUTHORITIES:

1. **Develop** health data governance frameworks that provide adequate processes for guiding health data use and data sharing across organisations while protecting patients' privacy.

2. **Clarify** the impact of the General Data Protection Regulation (GDPR) on health data processing and sharing. **Guide** healthcare providers on the practical implications of the new data protection framework. **Consult** stakeholders throughout the implementation phase of the new GDPR to ensure a harmonised enforcement.

3. **Encourage** the development of workflow management profiles and standards supporting federated architectures that enable inter-organisation shared workflows in a dynamic way, both at regional and national level.

JOINT ACTIONS BY MEMBER STATES AND HEALTH ICT VENDORS:

1. **Keep** expanding the set of use cases and the related supporting profiles and terminologies that enable health record sharing.

2. **Finance** further research into improving health ICT tools and systems for information management, knowledge representation, dynamic workflow optimisation and decision support.

1. INTRODUCTION

Currently, care workflows are routinely defined by best practices set by multidisciplinary teams within a given care organisation; they cover a specific disease and a standard patient profile. Once defined, workflows setting out the actions for caregivers and patients are often only available on paper, and eventually on digital format when added to individual operational clinical ICT systems. Given how these workflows are developed, they often cannot span multiple organisations; they are overly generic and too inflexible. They cannot adapt to individual patient characteristics or to situations diverging from the standard case in a given guideline.

Currently, disease-specific guidelines are primarily based on medical knowledge and statistical evidence published in scientific journals or generated by clinical trials. However, when a patient's profile does not correspond with the one described in the clinical guideline, the doctor is forced to deviate from standard practice. Such static guidelines and care pathways hinder delivery of truly 'person centred' care. This is because they approach treating patients with the same disease and similar characteristics in the same way, rather than adapting to the specific needs of the individual patient.

> **SHARED AND DYNAMIC CARE WORKFLOWS**
>
> The concept of shared and dynamic care workflows refers to an optimal, stakeholder-specific and ever adapting organisation of the activities performed in the context of disease prevention, diagnosis, treatment and follow-up by Integrated Care teams.

This lack of a patient-centric approach also explains why current care pathway technologies struggle to adequately address the challenge of patients living with multiple conditions (comorbidities) and who are poly-medicated. An ageing European population means this challenge will become more common [1] [2]. Therefore, approaches that focus on a single pathway for a single disease in isolation will become increasingly ineffective and inefficient.

Instead, we need a more dynamic approach, with adaptable workflows suitable for a dynamic operational, clinical and societal context. There are many circumstances that can alter during the patient journey; where a new clinical condition is diagnosed; or results from a diagnostic test differ from those expected; a patient's response to treatment varies; patient preferences change; or fresh medical insights arise such as a new contraindication. Even minor disruptions (a patient's transport does not show up, the doctor has an emergency and cancels an appointment or a diagnostic device is unavailable), if not taken into account, can undermine the experience and outcomes for both patient and care team.
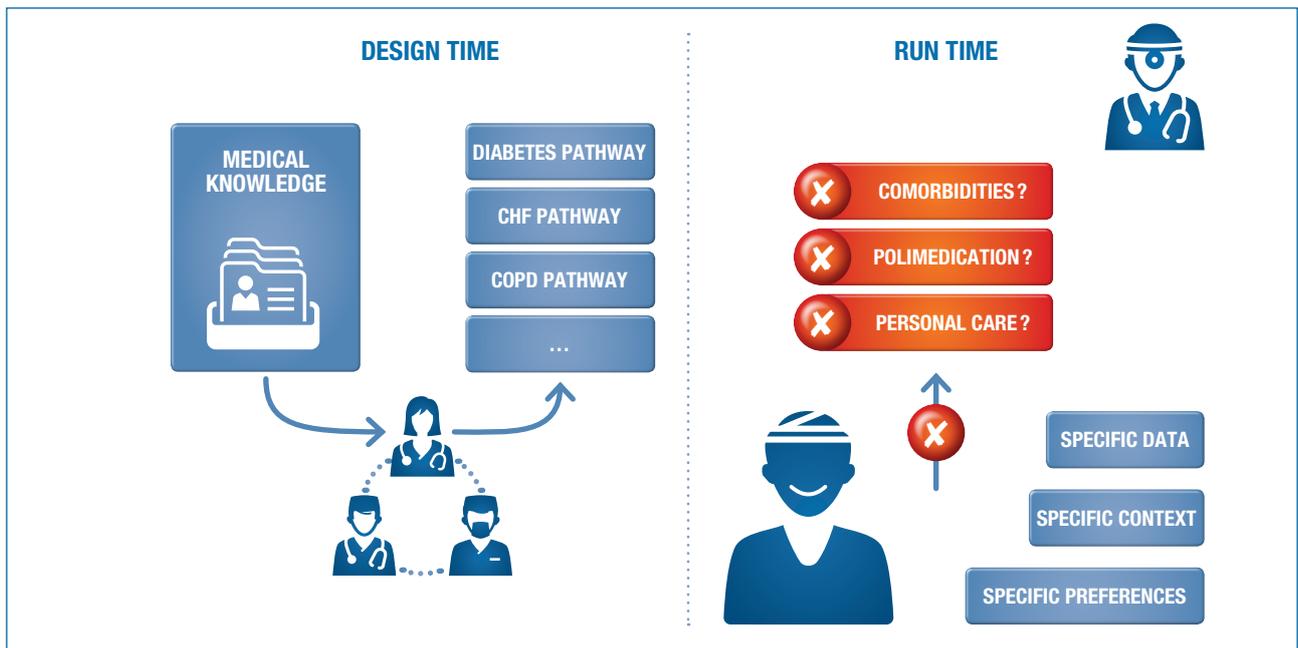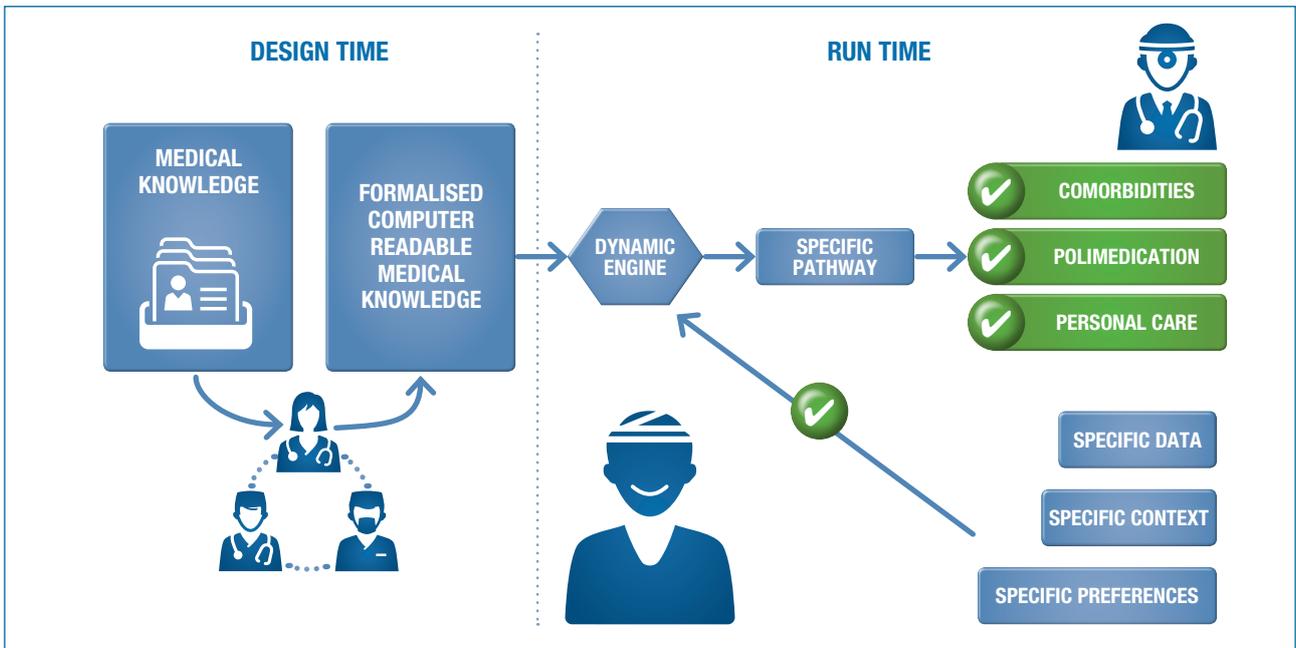

FIGURE 1. FIXED WORKFLOWS

FIGURE 2. DYNAMIC WORKFLOWS

Source: Agfa HealthCare

The increasing number of patients with comorbidities is already placing substantial financial and operational burdens on health and social care systems. As highlighted by the Call for Action of the Integrated Care Alliance (www.integratedcarealliance.org), this shift in population health needs demands both better coordination between health and social care systems and an inter-disciplinary approach.

We need to develop Clinical Decision Support systems, clinical guidelines and care pathways that can cope with the range of medical and social conditions and the ever-changing clinical and social contexts. As already observed, existing static pathways struggle to meet these needs. Even where using a well-designed care pathway, such as that for diabetes, the patient may have, or may develop, unforeseen conditions or complications that may render the pathway ineffective.

2. INTEGRATED CARE WORKFLOWS: OPPORTUNITIES AND CHALLENGES

2.1 OPPORTUNITIES

It is feasible to create shared and dynamic care workflows for Integrated Care teams that respond to clinical and operational changes, optimise the sequence and timing of required actions across organisational boundaries and allow information sharing between all stakeholders in the care pathway. Such workflows will be critical to achieving sustainable Integrated Care models.

Ultimately, building shared and dynamic workflows that take into consideration all stakeholders' goals can:

1. HELP PATIENTS AND CARE PROVIDERS WORK AS A COORDINATED TEAM
2. ACCELERATE CLINICAL DECISION MAKING
3. SUPPORT PERSONALISED AND INTEGRATED HEALTH AND SOCIAL CARE
4. INCREASE CARE QUALITY AND MANAGE COSTS MORE EFFECTIVELY

Comparing dynamic versus static workflows is similar to the difference between GPS guidance and a route planner. The router planner defines a route in advance, which can be printed out. However, it cannot adapt to incidents or developments "en route" such as road works or traffic jams. In contrast, a GPS shows the current position relative to traffic jams and road works, allowing optimal route planning in real time. In a smart city, GPS devices share information so that the overall traffic is optimised by coordinating each car's route according to the current capacity of the road system and conditions. A similar approach can be used in shared and dynamic workflows in health and social care; we could even refer to them as "socio-clinical GPS".

Given the level of information and resources involved, developing shared and dynamic workflows for Integrated Care teams needs ICT support. Combining all medical, operational, social and financial aspects is far too complex a task to be managed otherwise. As well as sharing patients' clinical and social data, dynamic workflows rely on ICT systems to provide all stakeholders with accurate information on the status of the distributed and coordinated activities across multiple organisations.

Effective shared and dynamic workflows require access to "just-in-time" assessment of the patient's condition, as well as ad-hoc clinical decision support that can access a large body of formalised, computer-readable medical knowledge and evidence.

2.2 CHALLENGES

Despite the promise of shared and dynamic workflows for improving healthcare delivery, a number of hurdles remain. Cultural, legal and financial challenges already hinder data sharing and greater coordination across the care pathway. This is exacerbated by some clinicians' lack of faith in the ability of ICT solutions to provide effective solutions.

We need to acknowledge that too often ICT systems have failed to meet expectations. They have not succeeded in helping professionals to make the right decisions, at the right time and for the right patient. Decision support systems and support for clinical pathways fail because they are insufficiently context-aware and patient specific. Comorbidity is a typical example of where the system should adapt and create a new pathway based on existing medical knowledge.

Just In Time (JIT) technology may help overcome this, by building on the existing but ever increasing medical knowledge, updated clinical information and global context of the patient, past experiences and new evidence coming from continuous analysis of existing data.

However, there are several challenges preventing the development and uptake of Integrated Care pathways, including those faced by JIT technology. We outline six key aspects:

1. JOINT ANALYSIS OF MULTI-SOURCED (BIG) DATA

Evidence-based medicine requires analysing massive amounts of multi-modal and multi-sourced (Big) Data. Business Intelligence software is increasingly used – in isolation - to process financial and operational data. However, the greatest value of systems for diagnostic and therapeutic activities will only be realised when operational, financial and clinical data are linked and processed jointly. Processing massive amounts of data can uncover hidden patterns and create insights, complementing traditional approaches to clinical research. Data analytics activities must extend beyond traditional Business Intelligence dashboards (descriptive analytics) towards predictive analytics (predicting the future by looking back) and prescriptive analytics (decision support).

2. LIMITS OF CURRENT REASONING ENGINES

To cope with the complexity stemming from comorbidities, Decision Support Systems will need to assess huge amounts of medical knowledge triggering a "combinatorial explosion". Reasoning engines face a huge challenge from an exponential explosion of possibilities, options in decision support systems, covering multiple domains simultaneously and just-in-time contextual changes. Ontology-based reasoning and inference are usually the domain of academic settings, that typically use limited amounts of data or small ontologies. The transition to a clinical setting, with huge amounts of data, may present serious challenges that will hinder the operational usage of semantic technologies. Yet standards are emerging that do address the preparation, operation and presentation of semantic operations. In addition, Cloud Computing offers the potential to reduce the logistical, financial and technical barriers [3].

3. INFORMATION GOVERNANCE AND CONSENT

Perhaps the greatest roadblock for the success of Integrated Care workflows systems is the lack of health data governance frameworks and infrastructures enabling all stakeholders to share common processes. Foremost among the needs of such systems is a mechanism to share and observe patient's wishes. For example, in patients with end-of-life conditions, all emergency services should be aware of the patient's choices regarding treatment or care settings. Bluntly speaking, we need adequate data governance frameworks to let us respect patients' dying wishes, among other things. This requires common identity management not just for patients but also for carers, supported by information quality assurance and control mechanisms.
As the English NHS care data project showed recently, high-profile, costly national projects can be seriously undermined or even fail due to inadequate data governance frameworks and lack of social education about secondary use of data.

4. LIMITS OF REGIONAL AND NATIONAL eHEALTH INFRASTRUCTURES

Managing shared and dynamic workflows across multiple organisations poses an additional challenge. These need to be designed to support the compounding and sharing of inter-organisation shared workflows in a dynamic way at the regional or national levels. The traditional workflow engines, centralised at the regional or national level, are unlikely to support such compounding; rather federated workflow architectures will be needed.

5. SHARING SEMANTICALLY RICH HEALTH RECORDS

The semantic interoperability needed to share health records with robust structured data remains a challenge, especially when spanning settings and provider organisations. By definition, dynamic workflows cannot be hard coded; they must retain the ability to evolve independently of the data needed to support their execution. This requires a proper architectural approach and a sound standardisation of different but collaborating services. Some are workflow centric (organising and tracking execution of tasks), others health data access and management centric with links between them. Such an approach to interoperability should bridge the infrastructural and semantic gaps between all stakeholders and institutions and will simplify the use of multi sourced (Big) data.

6. USABILITY OF ICT SYSTEMS

ICT systems need to be smart, useful and also usable, adapting naturally to the users' individual workflow and preferences. Adherence to pathways, dynamic or otherwise, is dependent on users' acceptance of ICT systems. Many ICT systems remain under-utilised as professionals perceive them as "more work", "not so useful" and even "difficult". Usability is the key, and both interfaces and workflows need to be adapted to specific stakeholder needs and user settings.
Additionally, Big Data presents a threat of information overload [4]. A delicate balance needs to be struck between "enough" and "too much". Clinicians particularly seek intuitive assistance rather than rigid processes. Given that it is impossible to foresee all potential scenarios, we need smart, adaptive, "just in time" systems that give the user what they need and nothing more. This is vital in home care, where individual circumstances can differ significantly and where the specificities of the users (conditions and age) require flexible and adapted user interfaces. Software needs to be both smart and kind.

3. COCIR RECOMMENDATIONS

To accelerate the development and uptake of shared and dynamic care workflows that will enable the delivery of Integrated Care, COCIR believes that the following actions need to be taken by Health ICT vendors, Member States and European Data Protection Authorities:

ACTIONS BY HEALTH ICT VENDORS

1. Deliver new technologies that can **combine different and heterogeneous data sources** across the whole spectrum of acute and chronic care, social care, wellness and beyond to demonstrate the feasibility of using Big Data in real world settings beyond lab or pilot environments.

2. Develop **new approaches** to cope with the **combinatorial explosion of data and medical knowledge**, new generation of reasoning and analytical engines to deal with the dynamic context of care delivery.

3. Design technology for information management and knowledge representation that takes into account the **complex relationship between technologies and their social and human context**. Develop ways of measuring the **effectiveness** and **"kindness" of new user interface approaches**.

ACTIONS BY MEMBER STATES AND EUROPEAN DATA PROTECTION AUTHORITIES

1. Develop **health data governance frameworks** that provide adequate processes for guiding health data use and data sharing across organisations, while at the same time protecting patients' privacy.

2. Clarify the **impact of General Data Protection Regulation** on **health data processing and sharing** and reach out to healthcare providers to guide them on the practical implications of the new data protection framework. Likewise, regulators should **consult industry and other stakeholders** throughout the implementation phase of the new General Data Protection Regulation to ensure a **harmonised enforcement of its provisions**.

3. Encourage the development of **workflow management profiles and standards supporting federated architectures** that enable inter-organisation shared workflows in a dynamic way, both at regional and national level (e.g. building upon IHE XDW).

JOINT ACTIONS BY MEMBER STATES AND HEALTH ICT VENDORS

1. Continue to expand the set of **use cases and the related supporting profiles** and **terminologies** that enable health record sharing (patient summaries, laboratory reports, etc.) in order to broaden the breadth of health information content being shared.

2. Finance further research into improving health ICT tools and systems for **information management, knowledge representation, dynamic workflow optimisation and decision support**.

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